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ABSTRACT

This participant's manual covers "People are People," the first module of a four-module training program for all individuals employed in programs funded by Oklahoma's Developmental Disabilities Services Division. This includes van drivers, recreation workers, residential staff, administrators, case managers, secretarial/clerical staff, vocational staff, advocates, physicians, psychologists, and others. The primary objective of the module is to have the participant understand and apply the concept of looking at individuals with developmental disabilities as people rather than as products of their disability. Secondary objectives include defining and using "People First" language, identifying criteria involved in the term "developmental disability," describing common developmental disabilities, and listing three statistics concerning people with developmental disabilities. The module includes the primary and secondary objectives, a text and question format that allows participants to become actively involved in the learning process, information from transparencies used in training, and copies of handouts. (JDD)

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MODULE ONE

Foundation Level Training

People are People

Participant's Manual

Department of Human Services
Developmental Disabilities
Services Division

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MODULE ONE

Foundation Level Training

People are People

Participant's Manual

Department of Human Services
Developmental Disabilities Services Division

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Foundation Level Training

INTRODUCTION

Foundation Level Training

People with developmental disabilities are PEOPLE FIRST. Their humanity is more important than their disabilities. They have dreams, hopes, likes and dislikes. They want to be loved and give love. They want to be respected by others and by themselves. They want challenges in their lives — a chance to accomplish things, to exercise their abilities and be productive citizens. They want to make a contribution to their communities. They want to have work that means something and that pays them enough to meet their basic needs.

They want a decent place to live in a decent neighborhood. They want to be as healthy as possible. They want the freedom to come and go as they choose, to be as independent as possible. They want privacy and the freedom to choose where and with whom they live. They want to be able to make choices about their daily lives; from what to wear and eat to when to go to bed.

In other words, they want what we want.

In the past, and even sometimes today, people with developmental disabilities have been seen only as people with needs which others must meet. Although this was never a true perspective — because people with developmental disabilities have had so few opportunities to exercise their talents and to give of themselves to others — it may have appeared to indeed be the situation.

This traditional viewpoint is one of the most important attitudes we must attempt to change — first in ourselves, then in others.

Today in Oklahoma, people with developmental disabilities are working at real jobs, volunteering in community service, being good

neighbors, participating in their government, attending classes, and in general, doing what all people do.

This foundation level training will give you an idea of who we serve, how we got here, where Oklahoma is today and what the future may hold. Most importantly, it will allow you to look at your own beliefs and hopefully develop an awareness that...

People are... People!

FOUNDATION LEVEL

Primary Objectives

Foundation training was developed to meet the primary training needs of staff, individuals, and family working with people with developmental disabilities. The primary objectives for the Foundation Level training course are to:

PRIMARY OBJECTIVES

Foundation Level Training

1. Provide all staff with a shared vision of what Oklahoma's system of services looks like, today and in the future.
2. Provide a consistent information, knowledge, and skill base for all individuals who serve people with developmental disabilities.
3. Prepare staff to become more effective members of the teams that provide assessment, planning, and delivery of services for individuals with developmental disabilities.
4. Improve the quality of communication and social interaction skills of staff who provide services.
5. Provide a functional definition of developmental disabilities and help staff understand common types of developmental disabilities.
6. Provide an understanding of historical issues influencing individuals with developmental disabilities and how these issues influence today's attitudes.
7. Provide staff and individuals with an understanding of the principle of normalization.
8. Provide a philosophy of services that is consistent with current state and national trends in service delivery.

PRIMARY OBJECTIVES

Foundation Level Training

9 Provide staff and individuals with a better awareness of the individual with developmental disabilities rights and legal issues surrounding service delivery.

10 Provide staff and individuals with an understanding of the services available within the State of Oklahoma and specifically, through the Developmental Disabilities Services Division.

11 Provide an understanding of mistreatment/ maltreatment, reporting measures for suspected abuse and neglect, and the importance of the use of non-aversive techniques.

12 Provide an introduction to future technological trends that may influence the quality of life of individuals with developmental disabilities.

13 Provide an awareness of the role of the state and the Statement of Beliefs that influence services for individuals with developmental disabilities.

For the objectives of the course to be met, participants will need to demonstrate mastery of the subjects presented by passing a written exam at the end of each module, completing in-class activities, and demonstrating specific skills through written exercises.

Foundation Level Modules

Foundation Training is composed of four modules of instruction:

MODULE ONE - "PEOPLE ARE PEOPLE"

Introduces the use of **People First** language. Defines the term, developmental disability, and describes some of the disabilities included in that term. Emphasis is placed on the concept of looking at individuals as *people rather than products of their disability.*

MODULE TWO - "CHANGING TIMES"

Traces the historical events that influenced how services for people with developmental disabilities developed across the nation and in Oklahoma. Emphasizes an understanding of what didn't work and why it didn't work so that we don't repeat the mistakes of the past. Also introduces the principle of normalization and the importance of role models.

MODULE THREE - "SYSTEMS AND POLICIES"

A snapshot of the State of Oklahoma service delivery system today, including public and private service providers, families, advocates, etc. Reaffirms the importance of individuals who work most closely with people with developmental disabilities.

MODULE FOUR - "THE NEW FRONTIERS"

Provides a "Vision of the Future," a blueprint which logically emerges from the previous three modules. It also provides a look at future technological trends that may influence the lives of individuals with developmental disabilities.

These modules are designed to be taught in consecutive order to give participants an awareness and understanding of the history, development and future goals of Oklahoma's Developmental

Disabilities Services Division. Each module includes learning objectives that will be addressed by the instructor through illustrated lectures, videos, and other audio/visual materials. Participants will take part in a variety of activities and exercises designed to clarify and illustrate each module's objectives.

Foundation Level Format

The Participant's Manual for Foundation training consists of four separately bound modules. Each module's format is organized into three sections:

LIST OF OBJECTIVES

Comprised of each module's Primary and Secondary objectives. Secondary objectives allow participants to accomplish mastery of the goals outlined by the module's Primary objective.

GUIDED NOTES

A text and question format that allows participants to become actively involved in the learning process. Most of the information in the transparencies shown by the instructor for each module are also included in right column boxes. Test questions will be taken from the Guided Notes section of the Participant's Manual. Participants are encouraged to complete all questions in their Manual as well as take additional notes. This information will be helpful in their employment settings long after training has ended.

HANDOUTS

Copies of the handouts emphasized in the training are located in the last section of the module. Other supplementary material may also be handed out by the instructor as training progresses.

MODULE ONE

People are People

TABLE OF CONTENTS

MODULE ONE - PEOPLE ARE PEOPLE

Objective One - People First Language 3
Using People First Language Exercise 5

Objective Two - Functional Definition of Developmental 6

Disability 6
Five Prerequisites 7
Seven Major Life Areas 7

Objective Three - Common Disabilities 10

Mental Retardation 10
Epilepsy 15
Cerebral Palsy 16
Autism 17
Other Conditions 19
Environments Which Disable 19

Objective Four - Statistics 21

MODULE ONE

People are People Objectives

MODULE ONE - LEARNING OBJECTIVES

OBJECTIVES

Primary Objective

Primary Objective:

Upon completion of this training and given the appropriate materials, the participant will be able to understand and apply the concept of looking at individuals with developmental disabilities as *people rather than as products of their disability.*

Secondary Objectives

Secondary Objectives:

- Define and be able to use People First language. Discuss how the application of labels affect the lives of individuals with developmental disabilities.
- Identify the criteria involved and write a functional definition of the term "developmental disability."
- Describe common developmental disabilities and write a brief description of each.
- List three statistics concerning people with developmental disabilities.

GUIDED NOTES

People are People

MODULE ONE - LEARNING OBJECTIVES

Objective 1: Define and be able to use People First language. Discuss how the application of labels affect the lives of individuals with developmental disabilities.

People are more than their disability. They smile, they laugh, they are proud of the quality of their work. They are somebody's spouse, brother, sister, son, or daughter. They are artists, musicians, athletes.

As recently as 1975, a leading medical guide labeled individuals with mental retardation as morons, imbeciles, and idiots. Words out of the dark ages. We are also familiar with the terms "mongoloid," "retardate," "vegetable," "quadriplegic," "epileptic." As a society we are becoming aware of how dehumanizing labels are. We know that all human beings are people and deserve our respect not because of who they are or what they are or how much they earn; but just because they are people.

People are... People!

Labels can result in prejudice and misconceptions. Labels can lead to individuals being shunned by society or even worse, as history shows, being tormented or neglected.

We know from research and personal experience that the first words we hear describe a person are the words we remember most clearly. The first words out of our mouths call attention to and focus on specific aspects of an individual. For example, if we

hear the terms "retarded child," or "epileptic woman," or "autistic man," the words imprinted on our minds are retarded, epileptic, or autistic. People tend to remember the disability; not the person, the citizen, or the child.

So, if we say something like "Mary is a disabled child," we are causing people to focus on the word "disabled" instead of focusing on Mary as just a child. Or if we say "the mentally retarded" or "the handicapped," we are ensuring that people will remember the fact that the group of individuals we are talking about are different: they have handicaps or disabilities. They are not (first) individuals who (secondarily) happen to have a disability.

Throughout this training, you will notice that the trainer is using terms such as:

"A child who has mental retardation."
"A woman with cerebral palsy."
"People with developmental disabilities."
"A citizen who has a disability."

This is called ***People First*** language. Progressive workers in this field use People First language.

We request that you also use People First language.

1. What is People First language? Give an example. _____
_____
_____
_____

2. The _____words out of our mouths are the ones people_____ .

3. How can the use of language that isn't People First language promote the labeling of individuals with developmental disabilities?
_____
_____

Participant's Name _____

Using People First Language

Directions: Rewrite each of the following statements using People First language.

1. Clara suffers from cerebral palsy.

_____

2. Manuel is deaf and dumb.

_____

3. Marian is crippled and slow.

_____

4. The disabled are often treated unfairly.

_____

5. Lewis is insane.

_____

6. Marc is restricted to a wheelchair.

_____

7. The mentally retarded child is often also physically disabled.

_____

8. Autistic children are slow to learn.

_____

Objective 2: Identify the criteria involved and write a functional definition of the term "developmental disability."

What is a developmental disability? Where did the term come from?

The term **developmental disability** does not describe a person. It is not a disease. It is not even one type of condition a person may have. A developmental disability is just that — a term that includes disabilities which occur in the developmental years (before the age of 22). It may be a physical or mental impairment or a combination of both. It is an umbrella term that includes a large number of disabilities, all of which have the common feature of occurring during the developmental years of life.

The term is also a **functional definition** — it focuses on how a disability interferes with a person's abilities and capacity to perform major life activities.

SOME POINTS TO THINK ABOUT:

- When a developmental disability occurs
- What can contribute to the occurrence of a developmental disability
- The life areas in which an individual's ability to function may be limited
- What types of disabilities may not qualify for services under the functional definition used by the State of Oklahoma, and why?

4. Why was there a need (especially concerning funding of programs) for a better definition of what constituted a developmental disability? _____

_____

_____

5. Why did rare conditions receive smaller funding amounts?

_____

_____

_____

A DEVELOPMENTAL DISABILITY IS A:

- Mental and/or physical impairment, which;
- Starts before age 22, and;
- Continues indefinitely or for an extended period of time, and;
- Results in a functional limitation in 3 or or more areas (described below), and the;
- Person needs an individually planned or coordinated combination or sequence of services.

Five prerequisites must be met before a condition may be described as a developmental disability. First, the disability must be the result of either a physical or mental impairment or both. Second, it must have occurred before the age of 22. Third, it must be **chronic**, meaning that it is likely to last either for the lifespan of that individual or for a very long time. Fourthly, the disability must result in significant functional limitations in three or more of the following life style areas, and fifth, there is a need for support.

SEVEN MAJOR LIFE AREAS

- **Self-care** activities are the things people do daily to meet their basic life needs. They include eating, personal hygiene and grooming.
- **Receptive and expressive language** are the verbal and nonverbal skills a person needs to understand others and to express his/her ideas and feelings.
- **Learning** is the ability to acquire new behaviors, perceptions and information; the ability to apply past experiences to new situations.
- **Mobility** is the ability to move from one place to another with or without mechanical aids.
- **Self-direction** is the ability to take care of oneself; the person is able to make sound personal decisions and protect his/her self-interests.
- **Capacity for independent living** describes a person's ability to live without extraordinary support in a way that is age-appropriate.
- **Economic self-sufficiency** describes a person's capacity to maintain adequate employment and financial support.

EXERCISE: DEFINITIONS

Write your personal definition of a "developmental disability."

_____

_____

_____

6. What is meant by the term "functional definition?"

_____

_____

_____

A functional definition focuses on how a disability interferes with a person's abilities and capacity to perform major life activities.

Mental retardation, epilepsy, autism, muscular dystrophy, spina bifida, and cystic fibrosis are examples of some conditions that fall under the term <u>developmental disabilities</u>. It is important to remember that there are **many** kinds of disabilities.

The disabilities discussed in this training are some of the most common forms but are by no means the **only** types.

7. List three or more disabilities that are not developmental disabilities. _____

_____

_____

8. Is a developmental disability a disease? Why or why not?

_____

_____

_____

9. Can a developmental disability be "cured?" Are these disabilities permanent? _____

_____

_____

SUMMARY

To summarize, developmental disabilities occur during the formative years of life from before birth up to the age of 22. Often, there is no known cause for a specific disability. Conditions such as physical and neurological impairments, premature birth, maternal drug and/or alcohol abuse, poor nutrition, and poverty may contribute to developmental disabilities. As previously stated, the one common factor of the above disabilities is that they occur in the developmental years of life and limit an individual's ability to function in **at least three of the major life areas** as described in the federal definition.

OTHER NOTES:

_____

_____

_____

_____

_____

_____

_____

Objective 3: Describe common developmental disabilities and write a brief description of each.

Definitions of developmental disabilities **may** be helpful in understanding the level of an individual's need. It is important to remember that the people with disabilities are the ultimate resources and the ultimate advocates in defining what they need.

Mental Retardation

Most people with mental retardation served by the State of Oklahoma meet the requirements for a developmental disability. They also may have more than one disabling condition (such as cerebral palsy or epilepsy). **Developmental disabilities and mental retardation are not the same. People with mental retardation have a developmental disability but not all people with developmental disabilities have mental retardation.**

The most recent definition of mental retardation by the American Association on Mental Retardation is as follows:

MENTAL RETARDATION refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas; communication, self-care, home living, social skills, community use, self direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.

In other words, the present definition states that mental retardation refers to *substantial limitations in present functioning.*

The four key elements are:

- Capabilities
- Environments
- Functioning
- Need for support

10. Explain what is meant by each of these elements when defining mental retardation.

Capabilities _____

_____

Environments _____

_____

Functioning _____

_____

CAUSES OF MENTAL RETARDATION

Mental retardation may stem from literally hundreds of possible causes such as:

- Genetic/chromosomal or inherited traits (Down Syndrome);
- Infections (encephalitis or meningitis), and metabolic problems (diabetes or hyperthyroidism);
- Environmental influences during pregnancy: lack of oxygen to the brain at birth, chemicals and drugs (including alcohol) ingested during pregnancy, exposure to radiation, and high temperature of a mother during early pregnancy;
- Other environmental factors (inadequate stimulation and love, or abuse, neglect, or other trauma during early childhood).

PRENATAL AND GENETIC CAUSES OF MENTAL RETARDATION

Damage to the fetus before birth can result in chromosomal abnormalities. Some of the conditions that result in chromosomal damage are:

PKU: Enzymes responsible for breaking down natural bodily poisons are absent

Down Syndrome: A chromosomal deficit

Structural Problems: Parts of the brain or body have failed to develop properly

PERINATAL CAUSES OF MENTAL RETARDATION

Difficulties during birth can lead to mental retardation. Some of these are:

Premature birth
Trauma during birth
Anoxia (lack of oxygen during birth)

CAUSES OF MENTAL RETARDATION

Prenatal and Genetic Causes

Prenatal and genetic causes (before birth) may result from chromosomal abnormalities in which parts of the chromosome that contributes information to the developing fetus are either defective or missing. Metabolic irregularities such as PKU where enzymes responsible for breaking down natural poisons in the body are missing can result in progressive damage to the brain. This condition can be corrected or minimized if detected early enough.

Structural problems where parts of the brain are missing or fail to develop properly can also lead to mental retardation.

Perinatal Causes

Perinatal causes (difficulties during birth) can result in mental retardation. Premature birth, trauma during birth or anoxia (a lack of oxygen to the brain) can result in damage to the brain and can result in mental retardation.

Postnatal Causes

Postnatal causes (after birth) such as the following can lead to mental retardation:

- **Trauma** - automobile accidents and child abuse are common causes of trauma
- **Poisons** - lead and carbon monoxide poisoning can result in mental retardation in children
- **Infections** - infections such as meningitis or encephalitis can inflame the brain or result in high fevers that can lead to mental retardation
- **Parasites** - not seen so much in this country but in other countries parasites can cause cysts or inflammation of the brain

Degenerative diseases such as muscular dystrophy can lead to the lessening of physical or mental abilities.

The above factors, along with others, can lead to mental retardation in a developing individual. Some are preventable through good prenatal care and others may be lessened by good care and education. One thing to remember is that 75-80 percent of the time, no cause for the disability is found.

The vast majority of people (90 percent or more) have only mild limitations and may require either limited or no additional assistance. There may be no known cause for their mental retardation. Social, family, and environmental conditions such as poverty, poor nutrition, maternal alcohol or drug abuse, premature birth, or early childhood abuse and neglect may contribute to this condition. People with mental retardation often need minimal support and have few or no additional handicapping conditions such as epilepsy or physical disabilities.

"We only serve a small number of all people labeled as mentally retarded. Most live, work and play with the rest of us in society and only need help occasionally from the rest of us."

People with more severe mental retardation may have additional handicapping conditions and are likely to need support in various areas of their life. Most have serious associated conditions which often result from the same cause as the mental retardation. Physical disabilities, epilepsy, and hearing and visual impairments are often seen in this group of people. It is important to note that we do not classify infants or children as developmentally disabled until they are older. Labels are not helpful in early childhood. They may in fact lead to low expectations and reduced levels of support. They are often inaccurate, and even when correct, they do nothing to change the kind of stimulation and nurturing a child needs to grow and develop.

SUMMARY

It is very important to remember that most children and adults with mental retardation are not in our service system. Either they function relatively independently on their own or their families provide the support necessary to meet their needs.

The second thing to remember is that many people will use our services intermittently. Regardless of the severity of their disability, they may have enough support available to them from their family, friends, and community that they will only need our help during times of personal crises.

It is very important to remember that most children and adults with mental retardation are not in our service system. Either they function relatively independently on their own or their family provides support necessary meet their needs.

There are, however, people who need a great deal of support socially, educationally, vocationally, and in terms of health care. Moreover, their families cannot provide such support. These are the people who make up the majority of the people we serve.

You will note that in this training, we are not focussing on why the developmental disability occurred but in how we can make people's lives better. We may not be able to cure their disability, but we can help them to maximize their potential.

Individuals with the same conditions may have different abilities. Although there may be similarities that help us in working with these individual's needs, we must always be aware the all people have different qualities that will shape their needs.

11. In what percentage of individuals with mental retardation do we know what caused the disability? _____

_____

_____

12. What may be some of the causes of mental retardation? Are we always aware of the causes? _____

_____

_____

13. Prenatal - _____ birth
Perinatal - _____ birth

14. List two prenatal causes of mental retardation. _____
_____

List two perinatal causes of mental retardation. _____

15. Is mental retardation a part of all developmental disabilities? Why or why not. _____
_____
_____

Epilepsy

Epilepsy is a chronic brain disorder characterized by seizures. These seizures can be described as uncontrolled body movements, unusual sensations (such as something crawling on the skin), altered perceptions (such as an awful smell), or various mixtures of movements and sensations that interfere with a person's normal function and behavior.

Seizures occur in approximately one to two percent of the general population. But as with mental retardation, only a very small number of people with epilepsy have conditions so severe as to be classified as developmentally disabled. Also, as noted earlier, people with one disability can have other disabilities as well. Thus, the percentages of people with a disability may be a duplicative number. Seizures can occur in many forms from severe body convulsions and unconsciousness to less intensive psychomotor epilepsy. An individual with psychomotor epilepsy may continue normal activities but exhibit amnesia or loss of awareness. The individual may not even realize that s/he has experienced a seizure.

Although the disease itself is not inherited, recent research suggests that, in some cases, the predisposition to the disease may be a hereditary trait.

People with epilepsy usually are only troubled by mild seizures that may be controlled with medication. They enjoy all aspects of society with little interference from their disability.

SUMMARY

Epilepsy can be controlled by medication in a large percentage of individuals. People with epilepsy may be restricted by a physician from certain activities such as driving, swimming or working on a ladder. With medication and supervision, protective and/or adaptive equipment — as well as support from others — people with even severe epilepsy can participate in most activities.

16. A large percentage of individuals with epilepsy can control their condition through_____ .

17. Is it possible that an individual not be aware that he or she is experiencing a seizure? What should you do in this situation?

_____

_____

_____

Cerebral Palsy

Cerebral palsy describes physical disabilities resulting from physical damage to the brain. This damage in turn affects muscle coordination. The difficulty may be so mild that it involves only fine motor skills, such as writing or sewing, or it may be severe enough that all motor activity is difficult and activities such as walking, talking and taking care of personal needs are hindered.

These motor activities usually result from damage to the brain either before, during, or after birth. They can arise from a variety of reasons including inherited metabolic conditions and diseases such as Rubella or toxemia during pregnancy. Oxygen deficiency and trauma during delivery can also result in cerebral palsy. Evidence of brain damage may not show up until several months

after birth and, in some cases, may not be recognized for several years.

Cerebral palsy is not progressive (it does not get worse). It is not contagious. It cannot be cured. However, as will be seen in the section on technology, there are wonderful new technological developments — wheelchairs which can be activated by blowing air through a tube, "talking" communication boards, electronic methods of muscle movement — that allow the individual with cerebral palsy to live a full life. In addition, physical therapy, speech therapy, and in some cases, orthopaedic surgery allow an individual to compensate for the disability.

SUMMARY

As the child with cerebral palsy grows, he or she may require services such as in-home support, continuing therapy, vocational training, adapted environments and/or equipment, living accommodations, transportation, recreation/leisure programs, and employment opportunities. Above all, people with cerebral palsy need — as do all of us — the opportunity to live as normally as possible in our society.

18. The condition of cerebral palsy results from physical damage to what part of the body? _____

_____

19. What types of support can help an individual with cerebral palsy compensate for his or her condition? _____

_____

Autism

Autism is usually present at birth but may not diagnosed before the age of three. It results in the child being unable to communicate effectively or process information from his or her environment. Children with autism may appear withdrawn and unresponsive, although in some cases such children

may also possess exceptional ability in areas such as music or mathematics. Autism is characterized as a disturbance in the following areas:

- speech and language
- rate of development
- ability to relate to people and things
- perception
- use of mannerisms

Individuals with autism may have difficulty in perceiving the world around them as other people perceive it. They may also has difficulty in communicating their perceptions to other individuals. These characteristics usually begin before the age of three and may range from mild to severe. "Autistic-like" behavior is a term often used to describe the repetitive behaviors and lack of awareness of their environment that people with autism may display.

It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.

The cause or causes of autism are still under investigation at this time but we do know that autism is not caused by specific types of parenting as was once suggested. It is a sad commentary that parents, especially mothers, have had a long history of being unfairly blamed by professionals for their child's disability.

SUMMARY

People with autism have a difficult time dealing with their environment; they may desire familiar things and set routines. Changes in routine or environment can be very disturbing. Maturation may be slowed and there may be a lack of physical, social and learning skill development. People with autism can benefit from structured programs that stress social and language skills as well as adaptive methods for dealing with their environments.

20. A disturbance in what areas is classified as autism?

_____

_____

21. What type of activities may be disturbing to an individual with autism and why? Why are structured environments important?

_____

_____

_____

Other Conditions

Although the conditions just discussed — mental retardation, epilepsy, cerebral palsy and autism — make up the largest numbers of people with developmental disabilities, other conditions can produce disabilities also. Muscular dystrophy, spina bifida, cystic fibrosis, hearing impairment, and vision impairment are among the many types of disabilities that can interfere with an individual's physical development and ability to learn. If these are sufficiently severe to result in substantial functional limitations in three of the major life areas, they can be classified as developmental disabilities as defined previously.

ENVIRONMENTS WHICH DISABLE

Just as the bones and muscles of children and adults with cerebral palsy can be permanently damaged through lack of stimulation and proper positioning, there are behaviors and physical disabilities that can occur in other people with developmental disabilities because of the environment in which they live. For example, self-injurious behavior, aggressiveness, learned helplessness and/or inappropriate noise making are all behaviors that can be developed in a setting where human beings are not given love and nurturing, are surrounded by inappropriate role models, or are not given adequate physical care.

Also, the misuse of psychotropic drugs, inadequate physical therapy, and the frustration that develops from not being able to

communicate can cause additional behavioral and physical disabilities.

24. The lack of _____ and proper _____ can permanently damage the bones of adults and children who have cerebral palsy.

25. How can the environment in which someone lives contribute to inappropriate patterning behaviors? _____

_____

_____

Section Summary

26. Discuss the differences between:

- Mental Retardation
- Epilepsy
- Cerebral Palsy
- Autism

_____

_____

_____

_____

_____

_____

_____

Objective Four: List three statistics concerning people with developmental disabilities.

The National Organization on Disability produces the following national statistics, (Please remember that the following information is based on all disabilities, regardless of severity or age of onset):

- 43 million Americans have some type of physical or mental disability (17 percent of total population).
- 22 million Americans are hearing impaired; 2 million are deaf.
- 2.5 million are severely visually impaired, while 120,000 are totally blind and 600,000 are legally blind.
- For all age groups, females report higher percentages of physical functional limitations than do males.
- 2 million people with disabilities live in institutions, including nursing homes, mental hospitals, residential facilities and mental retardation facilities. Over 1.3 million are in nursing homes.
- On average, people with disabilities have less education, less income, fewer job opportunities and fewer social contacts than others.
- 8.2 million working aged adults with disabilities were unemployed at the beginning of 1990. People with disabilities are the most welfare dependent minority in the U.S.
- More than 46 percent of all people over 65 have some type of disability.
- More than 25 million people with disabilities are registered voters.
- There are approximately 177,000 Americans with Spinal Cord Injury.

27. Less than _____ percent of Oklahoman's have a developmental disability. Most live _____ and receive _____from the state.

28. Approximately _____ persons are currently served by programs in which the Developmental Disabilities Services Division (DDSD) participates.

29. What percentage of the total population of Americans have a physical or mental disability? _____

30. Why are people with developmental disabilities considered to be the most welfare dependent minority in the U.S.? _____

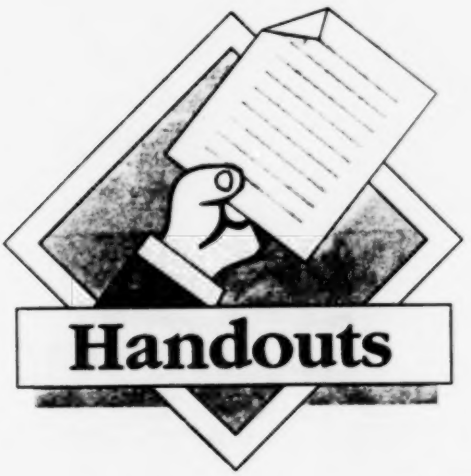
_____

_____

MODULE ONE

Foundation Level Training

People are People



You and I

By Elaine Popovich, Home Manager Lutheran Social Services, Midland, Michigan

I am a resident. You reside.
I am admitted. You move in.
I am aggressive. You are assertive.
I have a behavior problem.
You are rude.

I am noncompliant. You don't like being told what to do. When I ask you out for dinner, it's an outing. When you ask someone out, it's a date.

I don't know how many people have read the progress notes people write about me. I don't even know what is in there. You didn't speak to your best friend for a month after she read your journal.

I made mistakes during my check writing program. Someday I might get a bank account. You forgot to record some withdrawals from your account. The bank called to remind you.

I celebrated my birthday yesterday with five other residents and two staff members. I hope my family sends a card. Your family threw you a surprise party. Your brother couldn't make it from out of state. It sounded wonderful.

My case manager sends a report every month to my guardian. It says everything I did wrong and some things I did right. You are still mad at your sister for calling your mom after you got that speeding ticket.

I am on a special diet because I am five pounds over my ideal body weight. Your doctor gave up telling you to lose weight. I am learning household skills. You hate housework. I am learning leisure skills. Your shirt says you are a "couch potato."

After I do my budget tonight, I might get to go to McDonald's — if I have enough money. You were glad the new French restaurant took your charge card.

My case manager, psychologist, R.N., occupational therapist, physical therapist, nutritionist, and house staff set goals for me for the next year. You haven't decided what you want out of life.

Someday I will be discharged...maybe. You will move onward and upward.

(Reprinted with permission of The Cadre to Promote Normalization in Michigan from their newsletter, Framework.)

Department of Human Services
Developmental Disabilities Services Division
Community Relations Unit
P.O. Box 25352
Oklahoma City, OK 73125

It's the 'Person First" - Then the Disability

What do you see first?

- *The wheelchair?*
- *The physical problem?*
- *The person?*

If you saw a person in a wheelchair unable to get up the stairs into a building, would you say "there is a handicapped person unable to find a ramp?" Or would you say "there is a person with a disability who is handicapped by an inaccessible building?"

What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone — Jane Doe — who doesn't have a disability. You would give her name, where she lives, what she does, or what she is interested in — she like swimming, or eating Mexican food, or watching Robert Redford movies.

Why say it differently for a person with disabilities? Every person is made up of many characteristics — mental as well as physical — and few want to be identified only by their ability to play tennis or by their love for fried onions or by the mode that's on their face. Those are just parts of us.

In speaking or writing, remember that children or adults with disabilities are like everyone else — except they happen to have a disabled. Therefore, here are a few tips for improving your language related to disabilities and handicaps.

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disabled group — don't say "the disabled;" say "people with disabilities.
4. Don't give excessive praise or attention to a person with a disability; don't patronize them.
5. Choice and independence are important; let the person do or speak for him\herself as much as possible; if addressing an adult, say "Bill" instead of "Billy."
6. A disabled is a functional limitation that interferes with a person's ability to walk, hear, talk, learn, etc.; use handicap to describe a situation or barrier imposed by society, then environment, or oneself.

Say...	Instead of...
child with a disability	disabled or handicapped child
person with cerebral palsy	palsied, or C.P., or spastic
person who has...	afflicted, suffers from, victim
without speech, nonverbal	mute, or dumb
developmental delay	slow
emotional disorder, or mental illness	crazy or insane
person who is deaf or hard of hearing	deaf and dumb
uses a wheelchair	confined to a wheelchair
person with retardation	retarded
person with epilepsy	retarded epileptic
with Down Syndrome	mongoloid
has a learning disability	is learning disabled
nondisabled	normal, healthy
has a physical disability	crippled
congenital disability	birth defect
condition	disease (unless it is a disease)
seizures	fits
cleft lip	hare lip
mobility impaired	lame
medically involved, or has chronic illness	sickly
paralyzed	invalid or paralytic
has hemoplegia (paralysis of one side of the body)	hemiplegic
has quadriplegia (paralysis of both arms and legs)	quadriplegic
has paraplegia (loss of function in lower body only)	paraplegic
of short stature	dwarf or midget

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USING LANGUAGE APPROPRIATELY

1C

Over the past twenty years, Americans have become aware of how the language they use can express prejudice, and many racial, sexual, or religious labels are no longer heard. However, common language still contains many terms and expressions that are inaccurate or degrading labels for people who have disabilities.

Roughly up to 15% of the American population has disabilities. Over and over, people with disabilities say that the greatest barrier they face is not the disability itself, but instead the negative attitude and lack of acceptance of the rest of society.

Language reflects the existence of those attitudes in society. "Handicapism" shows up in speech just as racism and sexism once did. A first step toward changing attitudes is changing the way that we speak.

FOCUS ON THE INDIVIDUAL

Labels are so powerful that any unique identity of a person can be erased when the label is applied. Don't let a person's disability become his label — put it aside and see the individual instead. Instead of saying "my retarded son" say "my son who has mental retardation." A small difference, but it makes the child more important than the disability.

BE POSITIVE

Words like "pitiful" or "hopeless" convey negative feelings. A person who has cerebral palsy is not a "CP victim." Someone who has multiple sclerosis is not "stricken by MS." Think of the image that is created by these emotional words.

It is better to say "she uses a wheelchair" instead of "she is confined to a wheelchair," and "he walks with crutches" rather than "he is crippled." Not only is this more positive but more accurate. As Bob Peters wrote in the DISABILITY RAG, "A wheelchair does not confine...It allows its user to move around, to go to work, to travel, to play."

BE ACCURATE

The American vocabulary still contains a number of terms used to describe disabilities that are just plain inaccurate. Many of them are also very negative and degrading. A few examples are:

Deaf and dumb or deaf mute — out of date terms that were once used to describe a person who is deaf and can not speak. Many people with hearing impairments can speak, although their speech may be hard to understand.

Spastic — describes a muscle with sudden, involuntary spasms. It does not describe a person.

Suffering — saying that someone suffers from a disability implies that he or she is in constant pain from the disability. This is not usually the case.

Retard, gimp, paralytic — these words are put-downs. A person has mental retardation, walks with a limp, or is paralyzed.

It is also misleading to say "the disabled," which implies a group of people who are all alike and have a kind of separate status. The phrase "people with disabilities" is more appropriate and allows the emphasis to remain on the individual.

Avoid giving the impression that a disease is present when talking about a disability. A disability may result from a disease, such as polio, but it is not a disease. Neither is the person with the disability unhealthy or contagious. People with disabilities should not be referred to as "patients" or "cases" unless they are under medical care.

Remember that a disability is a condition that interferes with a person's ability to do something independently — walk, see, hear, learn, lift, etc. Other abilities are still present! People with disabilities, no matter how severe their disabilities, have capacities, gifts, contributions to make, if only we will give society opportunities to get to know them as individuals. The words we use must convey this message.

Those of us who work and live with people who have disabilities need to provide models for these better ways of using language. Making others aware of the stereotypes in their language will help make them aware of the barriers that exist for people who have disabilities.

PEAK PARENT CENTER, INC., 1988

2TIPS ON WRITING ABOUT PEOPLE WITH DISABILITIES

Think "people first." Refer to the person first and the disability second. Never equate a person with a disability — by referring to someone as "an epileptic," for example.

Avoid negative words like "unfortunate" or "stricken," "crippled" or "deaf and dumb." On the other hand, avoid casting a person with a disability as a superhuman model of courage.

A developmental disability is not a disease. Do not use medical terms unless the person you're writing about has an illness as well as a disability.

Do not confuse mental retardation with mental illness. "Mental retardation" refers to significantly sub-average intellectual functioning. "Mental illness" refers to disturbances of mental and emotional equilibrium.

Do not mention a subject's disability unless it is relevant to the story. If you aren't sure how to refer to a person's condition, ask.

Never refer to a person as "confined to a wheelchair." Wheelchairs enable people to escape confinement. A person with a mobility impairment uses a wheelchair.

Describe people without disabilities as "typical" rather than "normal." People with disabilities are certainly atypical but not necessarily abnormal.

Facts About:

OKLAHOMA DEPARTMENT OF HUMAN SERVICES

DEVELOPMENTAL DISABILITIES

A developmental disability is a severe, chronic disability of a person which:

- is attributable to a mental or physical impairment or a combination of mental and physical impairments;
- is manifested before the person reaches the age of 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self sufficiency;
- reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

It is difficult to pinpoint exactly how many Oklahomans have mental retardation because so many are able to function well and live in their own communities.

Simply stated, a person with mental retardation learns more slowly than others. According to the Association of Retarded Citizens/US, a person with mental retardation is "one who, from childhood, develops consistently at a below-average rate and experiences difficulty in learning, social adjustment and economic productivity."

The degree of mental retardation affects how much and how quickly a person who has mental retardation can learn. Mental retardation occurs once in every 33 people. Most are only mildly retarded.

Mental retardation is *not* mental illness. Mental retardation refers to a person's capability to think and reason. Mental illness is an emotional disturbance; there may be one occurrence or several which can develop at any time in a person's life. Like anyone else, a person with mental retardation may become emotionally disturbed or mentally ill.

CAUSES

More than 200 causes of mental retardation have been discovered. Some experts estimate that as many as 1,000 causes remain to be identified. Mental retardation can be caused by environmental factors, genetic factors or a combination of both.

- **Environmental factors** include everything that goes on around a person. Those factors could include an infection during pregnancy, a lack of oxygen at birth, encephalitis, meningitis, lead poisoning, alcohol, drug abuse or poor parenting.
- **Genetic factors** are specific traits or characteristics a person inherits from both parents at conception. The condition that causes mental retardation can come from one parent or from both—depending on whether the characteristic is a dominant or recessive one.
- **Both genetic and environmental factors** can combine to cause mental retardation. Some pregnant women can take certain types of medication and have perfectly normal babies. Others may be allergic to or suffer severe side effects from the same medication and have a baby with mental retardation.

CAN MENTAL RETARDATION BE CURED?

Some types of mental retardation can be prevented but there are no real cures yet—although researchers continue to search for one.

EDUCATION, TRAINING AND THERAPY

While people with mental retardation learn more slowly than other people, they have many of the same hopes, fears, joys, problems and needs that others do. People who have mental retardation have talents and abilities that should be developed through individualized education, job training and physical, occupational, music, speech and recreational therapies.

The end result of education, training and therapy is a better, more normal life for people who have the same rights and responsibilities as anyone else. It is a life that should not be denied to people who have mental retardation.

FOR MORE INFORMATION

Phone the area office hot lines nearest you:

AREA I (Enid) 1-800-522-1064
AREA II (Tulsa) 1-800-522-1075
AREA III (Pauls Valley) 1-800-522-1086

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The Arc

Q&A

a national organization on mental retardation

Mental Illness in Persons With Mental Retardation

By Steven Reiss, Ph.D., Director, Nisonger Center UAP, Ohio State University; with comments from Benjamin Goldberg, M.D., University of Western Ontario, and Ruth Ryan, M.D., University of Colorado Health Sciences.

What is mental health?

Mental health is a goal for all people, including those with mental retardation, not just those having difficulties. Mental health is an essential ingredient in the quality of life. The two main aspects of mental health are emotional well-being and rewarding social and interpersonal relationships. Emotional well-being is an important part of the gift of human life. Good social and interpersonal relationships are important for a rich and fulfilling life. People who have mental retardation are not in any way handicapped with regard to these human qualities — people with mental retardation are capable of a rewarding emotional life.

What is mental illness?

Mental illnesses are severe disturbances of behavior, mood, thought processes and/or social and interpersonal relationships. There are many different types of mental illnesses that are seen in people with mental retardation. Some of the most common types are:

- **Personality Disorders**. These are long-term problems in adjustment. There a number of different subtypes. These individuals might be described by one or more of the following: emotionally needy, inappropriately seeking attention, nonassertive, always getting into fights or trouble, volatile, unstable, or having a problem with anger.
- **Affective Disorders**. These are disturbances in mood, usually indicated by profound sadness and noticeable changes in eating, sleeping and energy levels. Sometimes a disorder is indicated by sudden bursts of euphoria.
- **Anxiety Disorders**. These are indicated by the presence of excessive fears, frequent complaints of bodily ailments (headaches, stomachaches, dizziness), and excessive nervousness lasting for weeks. These include panic disorder, excessive fears, and post-traumatic stress disorder.
- **Psychotic Disorders**. These can be indicated by gross deterioration in behavior from previous levels, extreme disorientation and extreme confusion. Common signs are confusion (thoughts may jump from one idea to the next), hearing voices that are not there, excessive resentment and poor impulse control and behavior or habits that impress others as strange.
- **Avoidant Disorder**. The individual is a loner who avoids peers for fear of rejection, embarrassment or criticism. This condition is sometimes mistaken for autism.
- **Paranoid Personality Disorder**. The individual is very suspicious of others and quick to feel insulted and belittled. People with this problem may be volatile, stubborn, difficult to get along with, unreasonable, and have a tendency to overreact (make mountains out of molehills).
- **Severe Behavior Problem**. These include self-injurious behavior, hyperactivity, extreme irritability and chronic aggression or antisocial behavior. Researchers have found that behavior problems are sometimes related to depression, paranoia, psychosis, underlying medical conditions or specific brain dysfunction.

What methods are used to diagnose mental illness in a person with mental retardation?

Mental illness should be diagnosed on Dimension II of the new American Association on Mental Retardation classification system (Luckasson et al, 1992). The diagnoses are best made by a qualified psychiatrist or clinical psychologist using the *Diagnostic and Statistical Manual of Mental Disorders*, published by the American Psychiatric Association in 1988. Standardized assessment instruments include the Reiss Screen for Maladaptive Behavior, the Psychopathology Inventory, Abberant Behavior Checklist, and Behavior Problems Inventory. These instruments should be used only as one part of a general assessment and never as the sole or primary basis for diagnosis and planning treatment.

Why do people with mental retardation develop mental illnesses and behavior problems?

Scientists still do not know for certain what causes most mental illness. Most researchers believe that both biological and psychological risk factors are involved, but to varying degrees depending on the specific disorder.

Some disorders may be wholly or largely caused by biochemical and structural abnormalities in the brain. Proclivities toward such abnormalities are sometimes inherited. Biochemical and structural abnormalities seem to be especially important in the occurrence of psychosis and explosive behavior. Life history and environment also may contribute to the development of the severity of psychosis and precipitate behavioral outbursts in susceptible individuals.

Some disorders may be wholly or largely caused by psychological factors, especially prolonged exposure to negative social conditions. The negative attitudes of the public toward people with mental retardation may promote the development of mental illnesses as a means of coping. For example, rebellion against negative social conditions can be labeled as "antisocial behavior;" the belief that a situation is hopeless often

Oklahomans with Developmental Disabilities

Estimated number, by age group, of Oklahomans with Developmental Disabilities (Using Gollay and Associate and Department of Human Services Prevalence Rates)

AGE	TOTAL OKLA. POP.	PERCENT of TOTAL	Gollay and Assoc. Est. (at 1.8% of pop.)	Okla. Dept. Hmn Svcs Est. (at 1.2% of pop.)
0 - 17	837,007	27	15,066	10,044
18 - 44	1,282,949	41	23,093	15,395
45 - 64	601,416	19	10,825	7,217
Over 64	424,213	13	7,635	5,090
Total	3,145,585	100	56,620	37,747
Percent	100		1.8	1.2

Source: UAP of Oklahoma Database, 1992-93

Estimated Number of Oklahomans with Developmental Disabilities based on Race and Ethnicity (using Gollay and Associates and DHS Prevalence Estimates)

Total Person Number		G&A at 1.8%	DHS at 1.2%	Hispanic Origin Number	G&A at 1.8%	DHS at 1.2%
Total	3,145,585	56,620	37,747	86,160	1,551	1,034
Anglo	2,583,512	46,503	31,002	35,924	647	431
Black	233,801	4,208	2,806	2,339	42	28
American Ind., Esk. Aleut	252,420	4,543	3,029	5,789	104	69
Asian, Pac Isl.	33,563	604	402	1,197	21	14
Other	42,289	761	507	40,911	736	491

Source: UAP of Oklahoma Database, 1992-93

Note: Information provided through the U.S. Department of Health and Human Services suggests that Black and Minority populations have higher prevalence of health problems than their non-minority same-age peers. Based on this data the DHS and G&A estimates may underrepresent the needs of people of color with regard to the actual prevalence of developmental disabilities in thesepopulations.

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Apple Computers, Educational Support, 2424 Ridgepoint Drive, Austin, TX 78754, for the use of their video ***Chapter One.***

The Learning House, 1548 Cherokee Rd., Louisville, KY, 40205, for the use of their audio cassette ***The Exceptional Parent Blues.***

20/20, Audience Information, 77 West 66th., 9th. Floor, New York, NY, for the use of their program ***Rumania's Children.***